#### 105TH CONGRESS 1ST SESSION

# H. R. 2923

To establish programs regarding early detection, diagnosis, and interventions for newborns and infants with hearing loss.

### IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 7, 1997

Mr. Walsh (for himself, Mr. McHugh, Mr. King of New York, Mrs. Maloney of New York, Mr. Kildee, Mr. Forbes, Mr. Boehlert, Mr. Lazio of New York, and Mr. Fossella) introduced the following bill; which was referred to the Committee on Commerce

## A BILL

- To establish programs regarding early detection, diagnosis, and interventions for newborns and infants with hearing loss.
  - 1 Be it enacted by the Senate and House of Representa-
  - 2 tives of the United States of America in Congress assembled,
  - 3 SECTION 1. SHORT TITLE.
  - 4 This Act may be cited as the "Early Hearing Loss
  - 5 Detection, Diagnosis, and Intervention Act of 1997".
  - 6 SEC. 2. PURPOSES.
  - 7 The purposes of this Act are to authorize statewide
  - 8 early detection, diagnosis, referral, and intervention net-
  - 9 works, technical assistance, a national applied research

- 1 program, and interagency and private sector collaboration
- 2 for policy development, in order to assist the States in
- 3 making progress toward the following goals:
- 4 (1) All babies born in hospitals in the United 5 States and its territories should be screened for 6 hearing loss before leaving the hospital (unless the 7 parents of the children object to the screening).
  - (2) Babies who are not born in hospitals should be screened within the first 3 months of life.
    - (3) Diagnostic audiologic testing, if indicated, should be performed in a timely manner to allow appropriate referral for treatment/intervention before the age of 6 months.
    - (4) All universal newborn hearing screening programs should include a component which ensures linkage to diagnosis and the community system of early intervention services.
    - (5) Public policy in early hearing detection, diagnosis, and intervention should be based on applied research and the recognition that infants, toddlers, and children who are deaf or hard-of-hearing have unique language, learning, and communication needs, and should be the result of consultation with pertinent public and private sectors.

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## SEC. 3. STATEWIDE EARLY DETECTION, DIAGNOSIS, AND 2 INTERVENTION NETWORKS. 3 The Secretary of Health and Human Services (in this Act referred to as the "Secretary", acting through the 5 Administrator of the Health Resources and Services Administration, shall make awards of grants or cooperative 6 7 agreements to develop statewide early detection, diagnosis, and intervention networks for the following purposes: 9 (1) To develop State capacity to support newborn hearing loss detection, diagnosis, and interven-10 11 tion. 12 (2) To monitor the extent to which hearing de-13 tection is conducted in birthing hospitals throughout 14 the State, and assist in the development of universal 15 newborn hearing detection programs in birthing hos-16 pitals and nonhospital birthing sites. 17 (3) To develop statewide models which ensure 18 effective screening, referral, and linkage with appro-19 priate diagnostic, medical, and qualified early inter-20 vention services, providers, and programs within the 21 community. 22 (4) To collect data on statewide early detection, 23 diagnosis, and intervention that can be used for ap-

plied research and policy development.

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## SEC. 4. TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND 2 APPLIED RESEARCH. 3 (a) Centers for Disease Control and Preven-TION.—The Secretary, acting through the Director of the 4 5 Centers for Disease Control and Prevention, shall make awards of grants or cooperative agreements to provide technical assistance to State agencies to complement an intramural program and to conduct applied research relat-9 ed to infant hearing detection, diagnosis, and treatment/ 10 intervention. The program shall carry out the following: 11 (1) Provide technical assistance on data collec-12 tion and management. 13 (2) Develop standardized procedures for data 14 management to ensure quality monitoring of infant 15 hearing loss detection, diagnosis, and intervention 16 programs. 17 (3) Study the costs and effectiveness of hearing 18 detection conducted by State-based programs in 19 order to answer issues of importance to national and 20 State policymakers. 21 (4) Identify the causes and risk factors for con-22 genital hearing loss that might lead to the develop-23 ment of preventive interventions. 24 (5) Study the effectiveness of early hearing de-25 tection, diagnosis, and treatment/intervention pro-

grams by assessing the health, developmental, cog-

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- nitive, and language status of these children at
  school age.
- 3 (6) Promote the sharing of data regarding early 4 hearing loss with State-based birth defects and de-
- 5 velopmental disabilities monitoring programs for the
- 6 purpose of identifying previously unknown causes of
- 7 hearing loss.
- 8 (b) National Institutes of Health.—The Direc-
- 9 tor of the National Institutes of Health, acting through
- 10 the Director of the National Institute on Deafness and
- 11 Other Communication Disorders, shall for purposes of this
- 12 Act carry out a program of research on the efficacy of
- 13 new screening techniques and technology, including clini-
- 14 cal trials of screening methods, studies on efficacy of inter-
- 15 vention, and related basic and applied research.

#### 16 SEC. 5. COORDINATION AND COLLABORATION.

- 17 (a) In General.—In carrying out programs under
- 18 this Act, the Administrator of the Health Resources and
- 19 Services Administration, the Director of the Centers for
- 20 Disease Control and Prevention, and the Director of the
- 21 National Institutes of Health shall collaborate and consult
- 22 with other Federal agencies; State and local agencies (in-
- 23 cluding those responsible for early intervention services
- 24 pursuant to part C of the Individuals with Disabilities
- 25 Education Act); consumer groups serving individuals who

- 1 are deaf and hard-of-hearing; persons who are deaf and
- 2 hard-of-hearing and their families; qualified professional
- 3 personnel who are proficient in deaf or hard-of-hearing
- 4 children's language and who possess the specialized knowl-
- 5 edge, skills, and attributes needed to serve deaf and hard-
- 6 of-hearing infants, toddlers, children, and their families;
- 7 other health and education professionals and organiza-
- 8 tions; third-party payers and managed care organizations;
- 9 and related commercial industries.
- 10 (b) Policy Development.—The Administrator of
- 11 the Health Resources and Services Administration, the Di-
- 12 rector of the Centers for Disease Control and Prevention,
- 13 and the Director of the National Institutes of Health shall
- 14 coordinate and collaborate on recommendations for policy
- 15 development at the Federal and State levels and with the
- 16 private sector, including consumer and professional based
- 17 organizations, with respect to early hearing detection, di-
- 18 agnosis, and treatment/intervention.
- 19 (c) STATE EARLY DETECTION, DIAGNOSIS, AND
- 20 Intervention Networks; Data Collection.—The
- 21 Administrator of the Health Resources and Services Ad-
- 22 ministration and the Director of the Centers for Disease
- 23 Control and Prevention shall coordinate and collaborate
- 24 in assisting States to establish early detection, diagnosis,

- 1 and intervention networks under section 3 and to develop
- 2 a data collection system under section 4.

#### 3 SEC. 6. AUTHORIZATION OF APPROPRIATIONS.

- 4 (a) Statewide Early Detection, Diagnosis, and
- 5 Intervention Networks.—For the purpose of carrying
- 6 out section 3, there are authorized to be appropriated
- 7 \$5,000,000 for fiscal year 1999, \$8,000,000 for fiscal year
- 8 2000, and such sums as may be necessary for each of the
- 9 fiscal years 2001 through 2003.
- 10 (b) TECHNICAL ASSISTANCE, DATA MANAGEMENT,
- 11 AND APPLIED RESEARCH.—
- 12 (1) Centers for disease control and pre-
- 13 VENTION.—For the purpose of carrying out section
- 14 4(a), there are authorized to be appropriated
- 15 \$5,000,000 for fiscal year 1999, \$7,000,000 for fis-
- 16 cal year 2000, and such sums as may be necessary
- for each of the fiscal years 2001 through 2003.
- 18 (2) National institutes of health.—For
- the purpose of carrying out section 4(b), there are
- authorized to be appropriated \$3,000,000 for fiscal
- 21 year 1999, \$4,000,000 for fiscal year 2000, and
- such sums as may be necessary for each of the fiscal
- 23 years 2001 through 2003.

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